Growing together: experience of parenting a premature infant in a rural area

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Aims

This paper details an in-depth exploration of the lived experience of parenting a premature infant in rural and remote Australia. This research aims to facilitate understanding of the everyday experiences of these families. To address this aim a model will be described called the *Practice of Parenting K.I.D.S. Model* which depicts the **K**ey **I**nteractions of **D**istance and **S**pace. The model invites reflection on, and understanding of, the experience of rural parents who have premature infants.

Background

Premature birth is the leading cause of disability worldwide[1,2], Infants born prematurely often require significant medical intervention and long-term multidisciplinary support in order to achieve their developmental potential.[3] Parents of premature infants must adjust to parenting a fragile infant that may experience long-term complex health issues.[4,5] The preterm birth and the complex needs of premature infants can have a substantial life-long impact on the nature of parenting and the relationship between the infant and their parents.[6-8]

Rural communities in Australia generally experience higher rates of preterm birth compared with metropolitan areas.[9] Yet, rural-based support services for families with premature infants are scarce and those services that do exist tend to be generalist in nature and might lack the specialised knowledge to meet the complex needs of these children.[10,11] Thus, it is likely that families in rural areas must parent their premature infant without local support, or travel vast distances to access specialist support.[5] Yet there are very few published accounts of the experiences and needs of rurally residing parents of premature infants to guide clinicians.[5,12] Thus, it appears that those with the highest rates of premature birth have the least access to specialist support services. Hence the research question for this paper is: *What is the lived experience of parenting a premature infant in a rural area?*

Methods

Methodology

This aim of this study was to gain an in-depth understanding of the experience of parenting a premature infant. It was for this reason that phenomenology of practice was chosen as the guiding methodology.[13,14] Phenomenology of practice seeks to understand and describe the pre-reflective

nature of everyday lived experience, in this case, parenting.[13,14] It is important to note that the model described in this paper is not posited as a theory or categorisation of parenting of premature infants. It is simply an invitation to further understanding of the experiences of these parents.

Participant recruitment

Parents of premature infants less than 35-weeks gestation were recruited via a metropolitan NICU, a rural community health service and an Aboriginal arts research program. Participants were either mailed a recruitment package or approached by Aboriginal staff at the Arts Research Program who were not part of the research team. Once participants had sufficient time to consider the information brochure and had returned a signed consent form a mutually convenient time and place for an interview was organised.

Data collection

Participants were invited to participate in two face to face semi-structured interviews. As the study was guided by phenomenology of practice the interviews focused on collecting experiential accounts of parenting premature infants.[13,14] Participants were also asked to bring a photograph or memento that reflected the experience for them, and these items were used as a stimulus for questions during the interview and as a reflective tool during data analysis. All interviews were audiotaped and transcribed verbatim. The transcripts and/or an audio-recording of the interview were returned to participants so they could ensure that the interview content reflected their lived experience.

Data analysis

Data analysis was guided by phenomenology of practice. Initially each interview was read and re-read while listening to the audio recording to gain a sense of the whole interview. Following this, each transcript was analysed phrase by phrase and each phrase assigned units of meaning. These units were further reflected on in the context of the whole interview, subsequent interviews and the research as whole. Thus, the parts of the analysis were ensured to be congruent with the whole. Gradually through this dialogical process, thematic ideas emerged from participants' accounts that described in-depth the experience of parenting a premature infant in a rural area. From these thematic ideas a model was developed to invite further understanding of the phenomenon.

Findings

Participants

Participants were thirteen mothers and three fathers who resided in a range of rural and remote settings within New South Wales (see Table 1). The participants represented thirteen different families and there were three married couples in the cohort. Four mothers but no fathers identified as Aboriginal. All fathers were married to one of the participant-mothers. All participants were married to, or in a de facto relationship with, the other parent of their premature infant at the time of their child's birth. However, three participants had separated from their partner at the time of the interviews. The prematurity of the infants ranged from 24-weeks to 34-weeks gestation at birth. The health issues of the premature infants ranged from those with no ongoing health issues to those with significant life-long disability.

The Practice of Parenting K.I.D.S. Model

From these experiential accounts the Practice of Parenting K.I.D.S. Model (see Figure 1) emerged. This model focused on the practice of parenting and those elements which influenced the nature of this practice in the lifeworld of the study participants. It consisted of a series of three concentric circles with the space for the practice of parenting, located centrally. This is a parent–infant intersubjective space where the practice of parenting occurred, and it was influenced by a number

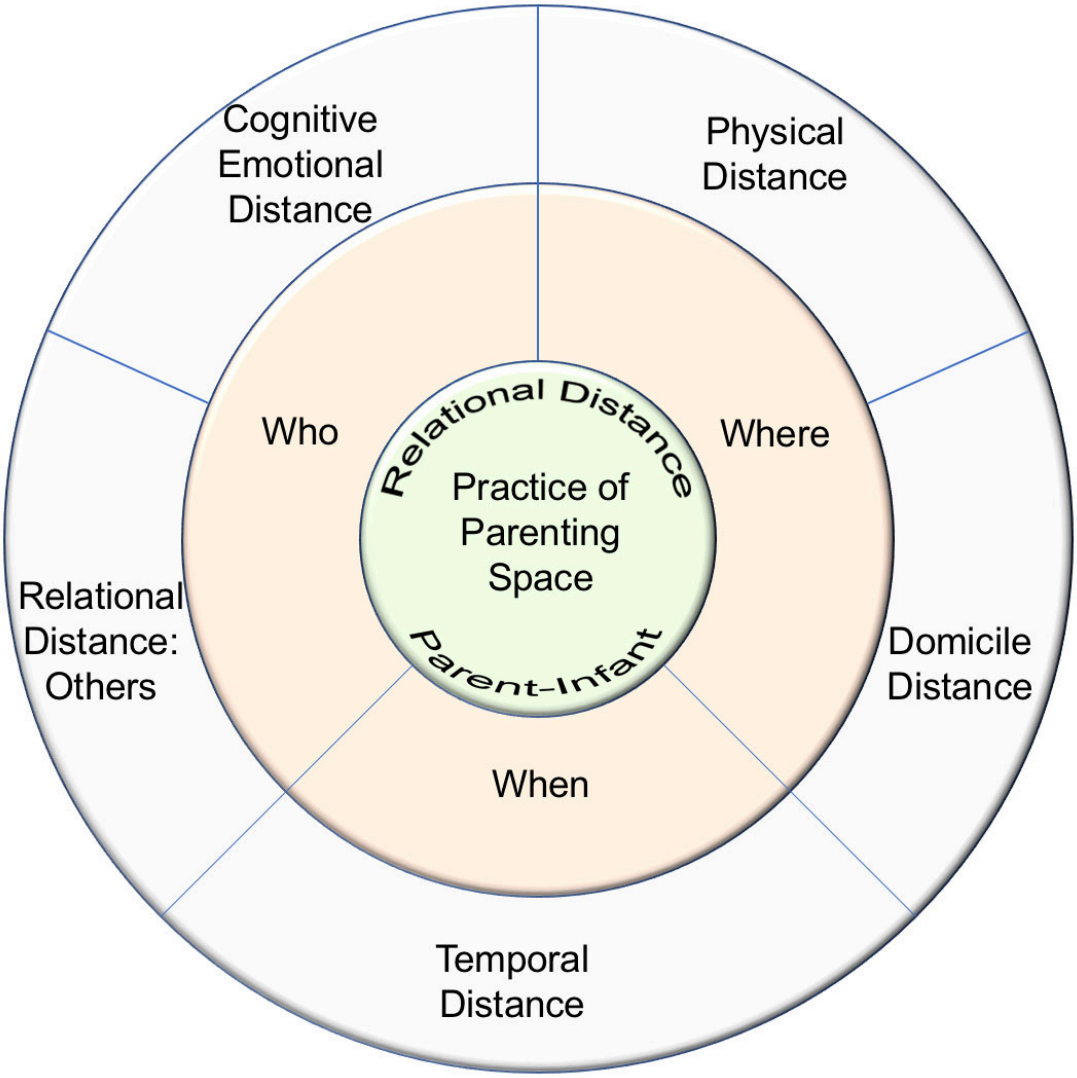
of forms of *distance* which surrounded it in the model. If this metaphorical space was increased for example by the reduction of stressors or distractions, then the parents could focus on the parenting, and meeting the needs of their child. Conversely, if there were competing demands for the parent's attention or focus, then the space for the practice of parenting was narrowed.

Table 1 **Descriptive Categories of Rurality and Number of Participants in each Category**

Modified Monash Model Category	Number of Participants	Descriptive Category
MM1	1	Metropolitan City
MM3	7	Regional Town
MM5	6	Rural Town
MM6	2	Remote Town

Note: There were no participants from towns classified as MM2, MM4, or MM7. One participant resided in a metropolitan city when her infant was born but moved to a regional town soon afterward.

Figure 1 **Practice of Parenting K.I.D.S. Model: Key Interactions of Distance and Space**



The forms of distance

An increase in distance emerged as a way of describing the barriers, stressors or events which rendered parenting of the premature infants more difficult. Many of these issues were likely to be experienced by all parents of premature infants such as the need to adjust to the foreign environment of the Neonatal Intensive Care Unit (NICU). But other issues were particular to the rurality of the experience, for example having to be transferred from the metropolitan NICU to a rural hospital, away from the intensive care they had come accustomed to:

> But when you leave… that's when it hit me that I couldn't just get out of my bed and walk through those doors and see my child. Like you go into hospital with a baby in your belly and you come home with nothing. So that was really hard. (Mother of 32-week premature infant)

Arguably any parent who had to leave a child in hospital while they are unwell might experience something similar. But for these participants, it often meant being many hundreds of kilometres away from their child. Often an act, kind word or empathetic gesture reduced the stress or trauma of their parenting experience. One mother related her experience while recovering in an intensive care ward herself:

> I made a friend go down [to the NICU]. I knew [friend] so well [and] this girl couldn't tell a lie to save her life. So I said to her "I need you to go down and make sure that he's okay." And she's like "I don't want to see your baby before you do." And I'm like "But that's not the point." I just needed to know. (Mother of 28-week premature infant)

When a stressor, barrier or issue was alleviated, this was described in this study as a reduction in distance and subsequently an increase in the space for the practice of parenting.

Within the model the space for the practice of parenting was closely surrounded by the *relational distance* between the parent and the infant. This parent–infant relational distance was the most critical form of distance because it had the most direct and profound influence over the space for parenting. One mother described distancing herself emotionally as she prepared herself that her daughter may not survive:

> I tried to put myself away from her, I didn't nurse her as much. I didn't spend as much time with her because I thought if I put myself away now and the worst case happens, I won't be as (pauses)—it won't be as hard a thing for me. (Mother of 27-week and 29-week premature infants)

This disruption of the parent-infant relationship may have the potential to have long-term consequences for the practice of parenting. The additional stressors particular to parenting a premature infant in a rural area may have further increased the relational distance between the participant and their child, and subsequently reduced the space for the practice of parenting.

The outermost circle contained the secondary forms of distance that were experienced by participants in this study; physical distance, domicile distance, temporal distance, relational distance with the other, and cognitive-emotional distance. These forms of distance were secondary as they tended to influence the space for the practice of parenting indirectly, by first influencing the relational distance between the parent and the infant, which subsequently influenced the space for the practice of parenting.

This intermediate circle contained the existential terms who, when, and where. Who, referred to people indirectly involved in the parenting interaction, other than the parent and the infant, for

example; the participant's partner, siblings of the premature infant, health professionals, relatives or friends. When, referred to the temporal aspects of parenting interactions, and participants' perception of time while parenting their premature infant. Where, referred to both the immediate milieu in which the practice of parenting occurred, and to the wider environmental contexts that may have influenced the nature of the parenting interaction. In the Practice of Parenting K.I.D.S. Model each segment of the circle containing the terms who, when, or where is linked to one or more of the secondary forms of distance in the outer circle depending on the influence each form of distance tended to have on the practice of parenting.

Physical distance

Physical distance was commonly experienced in the form of geographical distance, in particular the geographical distance these rural families had to negotiate in order to be with their infant in the NICU, or to access specialist health services. One father spoke of the impact that travelling to follow-up medical appointments had on his son's health

> [It] didn't do [our son] any good travelling all that distance, especially with how much sleep he was supposed to have and his oxygen needs, travelling in a car made giving him oxygen extremely difficult and sleeping in the sitting up position… it made his problem[s] worse. Well we believed it did because nearly every time that we went to [the metropolitan centre, our son] came back sick…. [he] were always better off if they could have stayed at home. (Father of three, 28-week premature infants)

Yet, physical distance was also experienced as anything that kept the participants from being physically close to their child:

> You couldn't even really touch her much, and she didn't like you touching her…. If you put your hand in and try and touch her she'd always pull away… It felt like she wasn't yours…. I don't think I had that connection that mothers have. (Mother of 26-week premature infant)

Common parenting activities necessitate physical contact, for example, holding, breastfeeding, or cuddling the infant. Yet the physical distance was a barrier to these activities, and subsequently reduced the space for the practice of parenting.

Relational distance with others

Relational distance with those other than the premature infant also had a poignant influence on the space for the practice of parenting. Sometimes the stressful demands of parenting a premature infant increased the relational distance between a participant and another person such as their partner, other family members, friends or health professionals. One mother related how it was difficult for friends to visit her and her daughter:

> Even when people used to ring to say they were coming around, they got the barrage of questions before they came! So, I probably put a few of my friends off coming to visit but that's the way it was. And I think that's probably one of the hard things too, just explaining to people that something as simple as a cold… is quite lethal to some of those kids. (Mother of 24-week premature infant)

Conversely, empathetic acts of support could reduce the relational distance between the participant and the other person. This in turn potentially reduced the relational distance between the parent and the infant.

> There was one particular midwife… [who] was really supportive... she came and gave me a cuddle and we went through what had happened…. She just took the time to sit down and

> talk about it... and she just sat with me for a while and gave me a hug. (Mother of 32-week premature infant)

For rurally residing families, the NICU experience usually occurred at a distance from their usual social and support networks, thus participants felt that those trying to support the them through this traumatic experience often struggled to empathise with their parenting needs.

Cognitive-emotional distance

Cognitive-emotional distance was illuminated in the study and encompassed participants' self-perception and feelings about their life as a parent of a premature infant. This form of distance was evident when participants felt their life, parenting a preterm infant, was at a distance from the life they had previously envisioned for themselves. As one mother lamented of her previous teaching career:

> I'd been teaching for so long, I didn't expect that teaching wouldn't be a part of my life; it was something I always wanted to do and ever since [my son was born] I've also looked at taking different career paths [but] there's nothing I could do because … who's going to look after [my son]? (Mother of 32-week premature infant)

In this example, the participant had to resign from her job in order to care for her son. Arguably this would be likely to reduce the physical and temporal distance between the participant and child. This is because the participant would likely be spending more time with her son infant and not at work. Yet, if she were to ruminate on the lost career, this could increase the cognitive-emotional distance because the participant's attention was on her lost career.

Domicile distance

Domicile distance was experienced as being distant from the familiar. While the geographical distance was a crucial element in this lived experience, an increase in the domicile distance often impacted parenting more profoundly. A father of a 27-week born premature infant related the difficulty of leaving the familiarity of the NICU and returning to the local rural hospital which was closer to home but unfamiliar, "[we experienced such] disappointment when we did bring her home, we felt that we had no support". Whenever participants were faced with unfamiliarity, such as an unfamiliar environment, health professional, hospital routine, or diagnosis, they needed to focus on adjusting to this unfamiliarity.

> The difference between [the rural hospital] and [the metropolitan NICU] is just poles apart. [The NICU has] got all the up to date equipment… everything is working like clockwork…. we just didn't feel as secure [in the rural hospital] I guess as what we did down there. If something was to go wrong… I don't know how the result would have [been]. [Mother of 26-week premature infant]

Having to adjust to the unfamiliar often drew their attention away from their premature infant and thereby reduced the space for the practice of parenting.

Temporal distance

Temporal distance was the distance between the participants' perception of the flow of time and their desired flow of time. This was not usually related to chronological time, but to the participants' subjective perception of time. For example, many participants spoke of time around the dramatic events of the premature birth passing very quickly, and this was incongruent with their desire to have more time to process and understand their situation. As a mother of three premature infants explained:

> [When they were born] I just didn't think about it very much and then the caesarean [happened, and] they were out before I even knew that they'd started… and there was lots of people but I didn't see any of them really. The neonatologist at the end said "We're taking them" and he was really nice and just took them all. (Mother of three, 28-week premature infants]

Alternatively, participants spoke of feeling as though time moved very slowly during other aspects of their experience, for example waiting for their infant to develop new skills such as walking or breastfeeding.

> She was still being tube fed at the time when we were in [the rural hospital] as well and I thought that she could handle more bottle feeds and they're like "No she can't" and I was like "Well yes she can" and I fought harder… I feel they were doing it too slowly, like she was ready for more than what they were doing. (Mother of 28-week premature infant)

If participants became frustrated with the temporal distance, this frustration could increase the parent–infant relational distance resulting in reduced space for parenting.

It was clear from these experiential accounts that the participants in this study experienced the stressors and barriers to parenting that were likely to be experienced by parents residing in metropolitan areas. Participants in this study also experienced additional stressors and barriers specific to residing rurally. These stressors and barriers emerged as the forms of distance which influenced the practice of parenting.

Discussion

The additional stressors and barriers to parenting posed by rural location may have negative long-term effects on the parenting of premature infants. Early in the experience the experiential forms of distance often led to a disconnection in the early foundational practice of parenting. This disconnection potentially altered the reciprocal development of relationship between the parent and their child. It is concerning that this loss of parenting has been found to potentially have considerable long-term implications[6,15,16] Parents may have been restricted from engaging in parenting activities due to the fragility of their infant's health, or not being able to stay in the hospital with their infant[17-20] The result is, that while the parent and their premature infant desperately tried to develop a relationship with one another, the usual reciprocal behavioural facilitators of this relationship may have been absent or inconsistent.[21] The additional stressors experienced by the rural families in this study such as being absent from their infant, may result in the premature infant's attempts at engaging and interacting with their parent being missed or misunderstood.[22,23] Thus, it is likely that the disruption of the early practice of parenting does not allow the parent or the infant to facilitate the blossoming of the first tentative parent–infant connections.[15,19,21,24]

It is possible that issues on the parental side of the parent–infant relationship may have the greater impact. In two systematic reviews of interventions to improve the relationship between mothers and preterm infants, the authors suggested that maternal issues such as mental health problems or being a teenage mother, may present more of an issue for attachment than infant health problems.[25,26] This is a concern for those caring for parents of premature infants from rural areas who are in general, more likely to be teenage parents[27], have higher rates of mental health issues, and fewer resources to deal with these issues such as financial income and local support.[28,29]

One of the key issues for participants was that rural based services and staff often lacked the specialised knowledge and skills to support them, or that a suitable support service simply did not exist. Yet, concurrently participants experienced that staff who had specialised knowledge were usually metropolitan based and thus often did not understand the rural-specific barriers and stressors. These families experienced additional stressors and barriers to developing their practice of parenting, yet often lacked the support that could facilitate this.

Strengths of this study include the chance for participants to review and reflect on the interview transcripts, the wide range of parenting characteristics and experiences collected and the in-depth experiential nature of the data. Limitations are that given rural areas are heterogenous in nature, these experiences may not be transferable to parents from other rural areas. None of the fathers in this study identified as Aboriginal and/or Torres Strait Islander. Given the high rates of premature birth in Aboriginal and/or Torres Strait Islander communities in Australia this is an important group to engage with for future research.

Conclusions

The experience of parenting a premature infant was traumatic for the families in this study and they experienced additional stressors due to residing rurally. By understanding the particular needs of rural families in-depth, it is anticipated health professionals can assist families more effectively and empathetically during their parenting experience. It is hoped that the Practice of Parenting K.I.D.S. Model might serve as a reflective tool for clinicians and those supporting families with premature infants to consider if their interactions are increasing the space of the practice of parenting or increasing one of the forms of distance and subsequently reducing the practice of parenting.

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Presenter

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